

Executive Summary

Idiopathic clubfoot (Congenital *Talipes Equinovarus*) is a condition in which the child is born with the hindfoot adducted, flexed and inverted, and the forefoot abducted and pronated in relation to the hindfoot. Neglected clubfoot results in significant impairment in body structure and function and may result in activity limitations and participation restrictions. For healthcare professionals, clubfoot is a clearly defined physical impairment. In contrast, for parents, guardians and children presenting with the condition, it is rarely clearly defined. Physical disability in Malawi, as elsewhere, harbours social and cultural implications that can readily influence the perception of a condition and its associated treatment-seeking behaviour. To date, there has been no systematic analysis of lay perceptions of clubfoot in Malawi.

The aim of this research, conducted by Anthrologica, was twofold. First, to determine new empirical data on the perspectives of clubfoot and its treatment in Malawi, amongst patients and their guardians. Secondly, to make recommendations to improve and develop the services of the Malawi National Clubfoot Programme (MNCP) through the qualitative analysis of patient and guardian's perspectives of clubfoot. The objective was to find ways in which the perceptions of patients and guardians could be meaningfully integrated into the biomedical framework of the MNCP to make it increasingly relevant and appropriate for the intended beneficiaries, and therefore advance the Programme towards its overall goal. The research contributes to our understanding of clubfoot and disability in Malawi and the wider African context.

Utilising anthropological methodology, the research produced sixty complete case studies, fifty-eight of which were cases of congenital idiopathic clubfoot. The majority of patients were male and presented with bilateral clubfoot. The left side was more commonly involved in unilateral cases. The majority of cases were undergoing treatment, several had defaulted treatment, but only one was a truly neglected case. It was found that most patients were the first or second born and only a small number had a close family member with clubfoot. The mother was the presenting guardian in over 80% of cases and mainly between the ages of fifteen and twenty-five at the time of the patients' birth. The majority of patients were under one year of age and had been diagnosed with clubfoot on their day of birth by a healthcare professional. Most patients arrived at an MNCP clinic by public transport, the majority journeying for more than one hour. Most guardians had no knowledge of the condition prior to its presentation in a close family member, and most subsequently received counselling at an MNCP clinic.

Part 1 of this report focuses upon the perceptions of clubfoot and its treatment as expressed by patients and their guardians. Attitudes, ideas and perceptions surrounding the condition were complex and interconnected. In the Malawian lexicon there is no direct translation for the English term 'clubfoot'. Instead various descriptive statements were employed in Chichewa, particularly *kopindika mapazi* (bent foot) and *mapazi opotoka mwachibadwa* (born with deformed feet). The language of disability used was also fraught with negative connotations and clubfoot was often stigmatised by its description as *kupunduka* (cripple). Such generic labels bring associations of abnormality and have the potential to influence all aspects of social interaction. The majority of guardians and patients claimed to have experienced a range of negative behaviour or negative attitudes as a direct result of clubfoot. This stigma originated from both inside and outside the family, although the fear of divorce, reprisals and being ostracised appeared to be regional variable. Fathers seldom presented patients at MNCP clinics and were largely disconnected from their child's treatment.

Many guardians attributed the occurrence of clubfoot to God, but elaborated this in a variety of ways: temptation; a gift; a test; as punishment; and fate. Others cited the Devil, witchcraft and cursing. Some suggested biological reasons. The theme of forgiveness was seen throughout many of the guardians' narratives. The majority were practising Christians for whom forgiveness was an important pillar of their faith. The complexities of causation and social responses were deeply entrenched in the perceptions of clubfoot and influenced the treatment seeking behaviour of the guardians interviewed.

Treatment seeking was rarely a straight forward process. The guardians' behaviour displayed a high level of pragmatism. The causative belief in the Will of God was not found to deter treatment. If guardians had not sought treatment or had defaulted from treatment when the patient was a baby, inability to walk or restricted movements as the child grew stimulated the re-engagement with biomedical treatment. In some cases, the impetus to re-start treatment came from older children themselves. A number of guardians expressed doubt that the treatment would be successful, yet came because a figure of authority (usually a healthcare professional) had instructed them to do so. Most thought the biomedical treatment (the Ponseti method) would result in the condition's physical correction. There was widespread denial that other healing practices, including consulting traditional doctors, had been employed, yet many guardians faced resistance to hospital-based treatment from within their family or community. This had caused many patients to present late.

The greatest barrier to seeking biomedical treatment for clubfoot was logistical. Transport was not only a financial concern but one of accessibility. Guardians expressed conflict between family and work responsibilities, and taking a child for prolonged treatment. Most preferred braces to castings which were easier to maintain, did not require weekly visits to a clinic and because correction in the feet was clearly visible. There were mixed views as to whether the casting process caused pain to the patient. The length of treatment was a cause for concern and had a negative impact upon compliance. That the feet appeared corrected following casting led many guardians to remove braces prematurely. This was a prominent reason for defaulting treatment and relapse. It is suggested that the MNCP continue to find ways of minimising the risk of default whilst maximising the opportunities for guardians to seek treatment.

This research was designed primarily to be of operational use to the MNCP. Part 2 of the report sets out strategic recommendations, based on the perspectives of patients and guardians. These are intended to support the Programme and enhance the provision and sustainable uptake of its services. Recommendations are made in eight interconnected areas:

- Increasing awareness
- Guardian advocacy
- Training, monitoring and evaluation (for clinical and counselling sides of the MNCP)
- Communication and information shared
- Sustainable and standardised policies
- Data collection
- Relations with other clubfoot programmes
- Ensuring the MNCP is patient centric